



Predictors of trajectories of epilepsy-specific quality of life among children newly diagnosed with epilepsy



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ABSTRACT

Objective: The objective of this study was to identify two-year trajectories of epilepsy-specific health-related quality of life (HRQOL) among children newly diagnosed with epilepsy and to evaluate the predictive value of a comprehensive set of medical, psychosocial, and family factors.

Methods: Ninety-four children with epilepsy (8.14 ± 2.37 years of age and 63% male) and their caregivers participated in this study. Caregivers completed the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE) and measures of psychological and family functioning at one month postdiagnosis. The QOLCE was also given at eight additional time points during the subsequent two years as a part of a large observational study in children with epilepsy. Adherence data were collected via MEMS TrackCaps, and medical information was collected through chart review.

Results: Unique trajectories were identified for the overall QOLCE scale, as well as the subscales. Most trajectory models for the QOLCE subscales contained at least one at-risk trajectory for children, indicating that there is a subgroup of children experiencing poor long-term HRQOL. Health-related quality-of-life trajectories remained predominantly stable during the two-year period following treatment initiation. The number of AEDs, internalizing problems, and externalizing problems emerged as the most consistent predictors across the HRQOL domains.

Significance: Medical and psychosocial interventions, such as cognitive-behavioral strategies, should target modifiable factors (e.g., internalizing symptoms, externalizing symptoms, number of AEDs trialed) shortly after diagnosis to improve HRQOL for children with epilepsy over the course of their disease.

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1. Introduction

Health-related quality of life (HRQOL) is a widely accepted health and patient-reported outcome measure that assesses the impact of an illness and its treatment on functioning [1,2]. Children with epilepsy are at an increased risk of poor HRQOL [3,4], particularly in the domains of emotional, behavioral, social, academic, and family functioning [5–10]. Assessing HRQOL in children with epilepsy allows healthcare professionals to have a broader conceptualization of the impact of epilepsy and antiepileptic drugs (AEDs) on the child and to make more informed decisions regarding medication, side effects, and the child's overall well-being. While many cross-sectional and longitudinal studies have been conducted examining HRQOL, few have identified the longitudinal course of HRQOL over time in children with epilepsy.

Abbreviations: AED, antiepileptic drug; HRQOL, health-related quality of life; SES, socioeconomic status.

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One exception is the HERQULES project, a prospective multisite study examining HRQOL and adherence in children with epilepsy at four points during the two years postdiagnosis. Ferro and colleagues [11] documented five trajectories of overall HRQOL with the majority of children being in the moderate-increasing (23%), high-increasing (32%), or high-stable (29%) trajectory group. The remaining children were in the moderate-decreasing (12%) or low-increasing (4%) group. Most of the children in the moderate-increasing, high-increasing, and high stable trajectory groups demonstrated clinically meaningful improvements in HRQOL over two years, while the children in the moderate-decreasing group experienced clinically significant declines in HRQOL [11]. The work by Ferro and colleagues provides important information regarding overall HRQOL trajectories over a two-year period but does not provide domain-specific information. Establishing domain-specific trajectories (e.g., depression) may be more helpful in identifying at-risk patients and determining targets for intervention to improve HRQOL given that interventions target a particular domain rather than general HRQOL. Another HERQULES study examined mean scores for the domains of HRQOL (e.g., depression, behavior, stigma) and found that scores tended to be lowest at baseline and highest two years later [3]. Although Speechley and colleagues provided domain

specific information, longitudinal HRQOL was examined over time by demonstrating a single, average model of HRQOL over two years, not trajectories [3]. Building from these two studies, our goal was to establish domain-specific HRQOL trajectories that would allow providers to identify particular aspects of HRQOL that need to be targeted with intervention (e.g., cognitive-behavioral therapy for emotional problems vs neuropsychological testing for neurocognitive problems). In addition, identification of the ideal timing regarding the delivery of such interventions is important.

Previous research has identified a number of predictors of HRQOL in children with epilepsy. A recent meta-analysis examined 12 risk factors for poor HRQOL in children with epilepsy and found that more severe seizure characteristics (i.e., type, frequency, severity, duration), AED characteristics (i.e., quantity, side effects), presence of a comorbid disorder (e.g., behavior, cognitive or emotional difficulties), and family characteristics (i.e., parental anxiety, socioeconomic status) were associated with poorer HRQOL [12]. Several longitudinal studies have also documented AED side effects, AED type, seizure frequency [13], cognitive problems, family demands, and family functioning [3,14] as predictors of HRQOL over time. Finally, the one existing study documenting overall HRQOL trajectories also found an increased quantity of AEDs, comorbid behavior or cognitive problems, parent depression, family demands, and family functioning to be associated with less favorable HRQOL trajectories [11]. It should be noted, however, that the relative contribution of each predictor to overall HRQOL and QOLCE subscales in a combined model has not been examined.

The primary objective of this study was to identify two-year trajectories of HRQOL following pediatric epilepsy treatment initiation using the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE), an epilepsy-specific measure of HRQOL. Although previous studies have established trajectories for the overall scale of the QOLCE and demonstrated mean models for the QOLCE subscales, no studies have established trajectories for the QOLCE subscales in a way that allows providers to identify at-risk domains of HRQOL and inform intervention type and timing. Our goal was to extend the literature by documenting trajectory groups across domains using established QOLCE subscales (e.g., physical restrictions, depression, behavior, memory, social interaction). Domain-specific HRQOL trajectories across nine time points will allow for the identification of children in need of a particular intervention at a specific time point. Our secondary aim was to examine the differential predictive value of medical, psychosocial, and family factors on domain-specific HRQOL. The recent meta-analysis [12] and existing longitudinal studies examining correlates of HRQOL [3,15] informed the compilation of a comprehensive set of predictor variables in order to identify the most critical predictors of overall and specific domains of epilepsy-specific HRQOL.

2. Methods

2.1. Participants and procedures

Participants were recruited and enrolled on the day of their epilepsy diagnosis and AED initiation from the New Onset Seizure Disorder Clinic for a two-year longitudinal study examining adherence and health outcomes. Parents of children who met the following inclusion criteria were approached by a trained research assistant: 1) 2–12 years old, 2) same day epilepsy diagnosis and AED initiation, 3) no comorbid medical conditions requiring daily medication, 4) no parent-reported developmental disorders, and 5) fluent in English. This study received prior approval by the hospital Institutional Review Board, and caregivers provided informed consent for each patient.

Caregivers completed a demographics form and received an electronic monitor to measure adherence to AED therapy. Subsequent study visits coincided with routine clinic appointments, which occurred approximately 1, 4, 7, 10, 13, 16, 19, 22, and 25 months postdiagnosis. During each visit, electronically monitored adherence data were

downloaded, and caregivers completed a battery of questionnaires. The current study examined the following parent-reported variables: epilepsy-specific quality of life, socioeconomic status (SES), side effects, child externalizing and internalizing behaviors, parent fears and concerns, and general family functioning. Disease-related variables were obtained through medical chart reviews and parent-report.

2.2. Measures

2.2.1. Demographic and disease characteristics

Background information such as child age and sex was provided by each primary caregiver via a demographics form. The Duncan scoring system, an occupation-based measure, was used to compute SES [16]. Scores were calculated for each family and ranged from 15 to 99, with higher scores reflecting higher SES.

Disease information such as number of AEDs, seizure type, etiology, and frequency of occurrence was obtained through a medical chart review. The number of AEDs signifies the total number of AEDs utilized during the two-year period. Caregivers completed the 19-item Pediatric Epilepsy Side Effects Questionnaire (PESQ) [17] regarding AED side effects experienced by the child. Scores range from 0–100, with higher scores representing more side effects. The PESQ has strong internal consistency and test-retest reliability [17]. Internal consistency reliability in this sample was 0.99. Seizure probability trajectory groups indicating the likelihood of patients having a seizure over the two-year study were previously identified and used as a marker of the seizure course in this study [18].

2.2.2. AED adherence

Adherence was assessed for the larger study utilizing a MEMS TrackCap, an electronic monitor that records the date and time the bottle was opened. Data were downloaded from the TrackCap at each study visit, and those data were previously used to identify trajectories of AED adherence over the first two years. Four long-term adherence trajectory groups were identified including severe early nonadherence, variable nonadherence, moderate nonadherence, and high adherence [18] and were utilized in the current paper.

2.2.3. Epilepsy-specific quality of life

Caregivers completed the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE), a 79-item parent-proxy report of the child's quality of life [19]. Scaled scores, ranging from 0–100 with higher scores reflecting better QOL, were calculated for total HRQOL and 17 subscales of the QOLCE. For ease of interpretation, QOLCE subscales are discussed in the following groups: physical domain [*physical restrictions* (10 items, $\alpha = 0.67$), *energy/fatigue* (2 items, $\alpha = 0.63$)], emotional domain [*depression* (4 items, $\alpha = 0.63$), *anxiety* (5 items, $\alpha = 0.79$), *control/helplessness* (4 items, $\alpha = 0.67$), *self-esteem* (5 items, $\alpha = 0.72$)], behavioral domain [*behavior* (16 items, $\alpha = 0.81$), *attention/concentration* (5 items, $\alpha = 0.90$)], neurocognitive domain [*memory* (6 items, $\alpha = 0.91$), *language* (8 items, $\alpha = 0.90$), *other cognitive* (3 items, $\alpha = 0.80$)], social domain [*social interaction* (5 items, $\alpha = 0.35$), *social activity* (2 items, $\alpha = 0.77$), *stigma* (1 item)], and overall [*general health* (1 item), *quality of life item* (1 item), *overall quality of life* (92 items, $\alpha = 0.95$)]. The QOLCE is a well established measure with good psychometric properties [19].

2.2.4. Psychological functioning

The Behavior Assessment System for Children—2nd Edition (BASC-2) [20] is a reliable and valid measure of behavioral and emotional difficulties. The parent-proxy version of the internalizing (e.g., anxiety, depressive symptoms) and externalizing (e.g., aggression, oppositional/conduct behaviors, hyperactivity) subscales was utilized in this study. Individual raw scores were compared with normative data for children of the same age and resulted in standardized *T*-scores, with *T*-scores above 65 representing at-risk functioning. Cronbach's alpha ranged from

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